

EXECUTIVE SUMMARY

AOA FURTHER ANALYSIS AND EVALUATION OF THE ADDGS PROJECT

PROJECT GOAL

This report summarizes findings from three related studies that extended the initial evaluation of the Alzheimer's Demonstration Grant to States program (ADDGS) to obtain additional information about the patterns of use and delivery of respite services. The goal of the project was to capitalize on the unique longitudinal qualities of the data from the ADDGS to provide a more detailed analysis of how: (1) families use respite services; (2) families evaluate respite services in light of their beliefs, culture, and need; and (3) providers can develop appropriate and successful respite services in their own communities.

ALZHEIMER'S DEMONSTRATION PROGRAM

The Alzheimer's Demonstration Grants to States (ADDGS) program was authorized through section 398 of the Public Health Service (PHS) Act (P.L. 78-410) as amended by Public Law 101-157, Home Health Care and Alzheimer's Disease Amendments of 1990, and by Public Law 105-379, the Health Professions Education Partnerships Act of 1998. *The goal of this legislation was to expand support services for persons with Alzheimer's Disease and their caregivers.* Special attention has been given to reaching hard-to-serve and underserved populations. The demonstration program was intended to assist grantees in planning, establishing, and operating demonstration programs in the following areas: (1) program development; (2) services delivery; and (3) information dissemination.

Fifteen grantees were selected through two rounds of competitive requests for proposals. In September of 1992, eleven states (*California, District of Columbia, Florida, Maine, Maryland, Michigan, Montana, Ohio, Oregon, Puerto Rico, South Carolina*) received a three-year Alzheimer's Demonstration Project grant award. In July of 1993, four additional states received a demonstration grant (*Georgia, Hawaii, North Carolina, Washington*). The individual grants were then extended to each site through FY 2000.

Unlike many federal programs, the Alzheimer's Demonstration has been characterized by great local diversity in design and implementation. Although every grantee has been responsible for the creation of respite services and outreach to hard-to-reach populations, each state (or territory) has developed and executed a program of outreach and support services that was specific to the unique needs and resources of their citizens. A second hallmark of the project has been the development of cooperative partnerships among public and private organizations to integrate the new programs and services effectively into existing service environments.

In January of 1997, the Final Report for the ADDGS project documented the accomplishments of the program (Montgomery et al., 1997). At that time, nearly seven thousand families (6,983) had been served and well over one million units of respite and support services (1,039,506) were delivered through the demonstration. Of particular interest was the success of the ADDGS project in reaching under-served and under represented populations (see also Montgomery et al. 1997). African Americans/Blacks, Hispanic/Latinos, Asian/Pacific Islanders, and Native Americans/Eskimos were served through the ADDGS in numbers that exceeded their proportion of the general United States' population.

BACKGROUND AND RATIONALE FOR PROJECT

What is Respite?

Respite is a term used to refer to a wide range of services intended to give temporary relief to families caring for disabled members. This concept of care developed in the United States as a corollary of the early 1970s deinstitutionalization movement for developmentally disabled children and adults (Cohen, 1982). As families assumed the primary responsibility for the developmentally disabled, the need for temporary relief from their caregiving responsibilities created a demand for respite services. Recognition, in the United States, of the parallel need for relief of family members caring for frail and disabled elderly did not emerge until the mid 1980s when formal respite services were initially developed as demonstration projects.

While there is general consensus that respite means "an interval of temporary relief," there is almost no agreement as to the composition of the services that are to provide relief. Respite programs have ranged from volunteers providing short periods of companionship to short stays in institutions. Services can be provided in a client's home (in-home services), in a group or institutional setting (out-of-home service), or in multiple settings (combination programs). Out-of-home services include foster homes, adult day care centers, respite facilities, nursing homes, and hospitals. The only element common to these services is the intent to provide a period of relief for caregivers.

Within the three general types of respite settings, there are a number of possible variations depending upon the level of care, the types of activities available to participants, and the duration and frequency of respite episodes. Programs may vary along a continuum from low to high levels of care, and respite episodes may range from short periods of a few hours to long stays of up to six weeks. Clients may be able to use services as frequently as once or twice a week or as infrequently as once or twice a year.

Contributions of this Project

Currently there is overwhelming consensus among families and service providers that respite services are the most desired and needed support for families caring for persons with Alzheimer's disease or other dementias. There is also a pervasive belief that respite care can relieve the burden of the caregiving situation and, perhaps, even allow families to continue to care for relatives who otherwise might have been institutionalized. This perspective tends to be accompanied by the belief that respite programs will reduce the costs of long term care by reducing or delaying the need for more costly forms of care.

To a large extent, any empirical evidence to demonstrate the psychological and monetary benefits of respite remains sparse and uneven because respite remains an amorphous notion that has not been systematically studied. Unlike pharmaceutical studies, which use rigid protocols to control the content and quantity of a treatment, respite as a treatment has varied widely in composition and quantity both among studies and within single studies. Insufficient attention has been given to describing service interventions or patterns of service use over time (Lawton, Brody and Saperstein, 1989; Montgomery and Borgatta, 1989).

The question as to whether respite services ultimately reduce the cost of long term care remains an important policy issue. Yet the question remains largely unanswered because little is truly known about how caregivers opt to use respite services when they are available. Despite growing evidence that respite services, indeed, do help families continue in their caregiving role for a longer period of time (see Montgomery and Kosloski, 1995), there is little systematic knowledge about long-term patterns of respite service use *in situ*.

Basic information about patterns of respite use is necessary for practitioners to plan and implement respite programs. For example, in a real life setting, how much respite will a family use? Over what period of time do families use respite and at what level of intensity? How do these patterns differ for different types of respite programs (i.e., in-home or ADC)? How do constraints in respite availability alter patterns of use? Are there differences in use patterns associated with type of caregiver (spouse/adult child) or with disability level of the elder or with geographic regions or by differing cultural backgrounds? Answers to these questions are extremely important for the development of effective and efficient support programs and long term care policies. This project entailed three related studies that were undertaken to address these critical questions about the use of respite services.

STUDY ONE: ASSESSING CULTURAL AND STRUCTURAL BARRIERS TO SERVICE USE

Purpose of Study One

The central purpose of study one was to identify differences among cultural groups in their beliefs about family caregiving and their views of respite services offered through the ADDGS program. The links between culture and belief systems, perceptions of service accessibility, and client satisfaction were explored in detail. For this study, culture was defined in terms of three variables: ethnicity, family relationship, and geographic location. Each of these dimensions of diversity was examined as a factor potentially affecting clients' beliefs about caregiving and views of program services.

Methods

Sample. Telephone interviews, using a computer assisted telephone interview (CATI) system, were conducted with a culturally diverse sample of 377 client caregivers from the ADDGS project. The sample included 45% White, 31% Black/African-American, and 25% Hispanic/Latino caregivers.

Measures. Eleven composite variables were constructed to measure aspects of caregivers' beliefs about aging and responsibilities for care. These measures included *affection for elder, obligation to care, family values, respect for elders, desired frequency of social contact, guilt at respite use, attitudes toward government assistance, satisfaction with help with caregiving, religiosity, strength of beliefs, and support provided by religious congregation*

Nine composite variables were constructed to measure caregivers' perceptions of access and/or barriers to service use. These included *client satisfaction, communication difficulties, clear expectations, access to services, friendliness of staff, shared values with staff, institutional barriers, trust in staff, and appropriateness of activities.*

Analyses. Analysis of variance was used to examine differences between cultural groups in beliefs systems. Multiple regression procedures were used to identify predictors of client satisfaction.

Findings

Attitudes and Beliefs

As anticipated, members of different ethnic, geographic, and relationship groups held markedly different beliefs about various aspects of family relationships, responsibilities for care, and the conditions for appropriate use of outside services. Differences were observed between ethnic groups on 9 of the 11 measures of caregiver beliefs and attitudes about filial care and responsibility. In contrast only one difference in beliefs was associated with geography and two differences were associated with the family relationship of the caregiver to the elder.

- Whites reported lower levels of affection for the care recipients and less adherence to family values. Whites also expressed the highest level of guilt for using support services and were least likely to endorse the responsibility of government to provide support services.
- Hispanic/Latinos reported the highest level of adherence to family values and the greatest respect for elders. As a group, Hispanics/Latinos were also most satisfied with the levels of social contact they currently experienced and the level of help they received.

- Black/African-Americans reported the highest levels of religiosity, the greatest strength of belief in God, and the highest levels of support from religious communities.
- Spouses expressed greater affection for the care recipients and greater obligation to provide care than did children or other groups of caregivers. Spouses also reported significantly less family conflict.
- Caregivers in urban areas reported greater respect for the elder than those residing in rural areas.

Cultural differences in views of services were identified for only two aspects of service programs. Hispanic/Latino caregivers reported greater difficulty with communication relative to other groups. Notably, Whites reported the lowest levels for accessibility of services.

Satisfaction

Perhaps the most important finding was that there were no differences in client satisfaction with the demonstration services associated with ethnicity, relationship to the elder, geographic location or type of respite. Moreover, all levels of satisfaction were uniformly high, averaging nearly 14 on a scale ranging from 3 (low) to 15 (high).

The most satisfied day care clients were those who: (1) received high levels of support and comfort from their religious congregation (2) had clear expectations regarding the program services; (3) judged the respite services to be appropriate for the client; and (4) perceived the “red tape” to be minimal.

Clients of in-home services were most satisfied when they: (1) had clear expectations regarding the program services; (2) perceived the respite services to be accessible at the times they need it; and (3) judged the program staff to be friendly.

Practice Implications

Four factors that are under the control of practitioners were found to be related to client satisfaction. These findings suggest that clients will be most satisfied when service providers:

- convey a clear understanding to caregivers as to what a respite program will and will not do in providing care for the individual with AD;
- reduce the amount of red tape associated with the program;
- provide activities that caregivers believe to be appropriate for their family members; and
- are flexible with the amount of service that is made available and the times at which it can be used.

STUDY TWO: IDENTIFICATION OF PROFILES OF RESPITE SERVICE USE

Purpose of Study Two

The primary purpose of study two was to identify and document long term profiles of respite use among a diverse sample of families caring for elders with dementia. These profiles are potentially useful planning tools for policy makers and service providers responsible for implementing effective and efficient respite programs. This study capitalized on the unique qualities of the data from the Alzheimer's Demonstration Grant to States (ADDGS) that have been gathered over the past seven years.

The diversity of caregivers and their caregiving contexts is now well established by a large body of research conducted over the past two decades. This study was undertaken with the expectation that diversity among caregivers and their contexts would likely be reflected in their patterns of respite use. Specifically, three sets of variables were investigated as plausible factors affecting patterns of service use: cultural differences; differing caregiving careers; and service availability.

Study Questions

Four basic questions concerning patterns of respite use among a diverse sample of families caring for an elder with dementia were addressed:

1. What is the duration of respite use?
2. How much respite is used?
3. How consistently or continuously do families use respite?
4. Do patterns of service use change over time?

Additionally, the analysis also focused on three related questions pertaining to differences in patterns of respite use that are likely to be associated with characteristics of families and/or providers:

5. Do patterns of respite use differ by type of respite service (e.g. in-home or day care)?
6. To what extent are patterns of respite use associated with characteristics of the caregiver or elder?
7. To what extent are patterns of respite use associated with characteristics of service providers?

Methods

Sample. Data were gathered from 4,369 client families and 122 service providers who participated in the ADDGS demonstration in the District of Columbia, Florida, Maine, Michigan, North Carolina, South Carolina, and Washington. Of the 2193 clients using day care services, 640 were brief users and 1553 were extended users. Of the 2690 clients using in-home services, 831 were brief users and 1859 were extended users.

Data Collection. Information about demographic and functional status of elders and caregivers was gathered as part of the client intake process. Data pertaining to clients' use of services were taken from providers' records. Telephone interviews were conducted with key staff members to obtain programmatic information from the 122 agencies providing respite services in day care and in-home settings.

Measures of Service Use. Although most previous studies have quantified the amount of service use in terms of total hours of respite used, this summary value does not capture the many ways that families may differ in their use of services. Families may vary in (1) the number

of hours that is used on each occasion, (2) the duration of time (e.g. number of months) over which a family actually uses services, (3) the continuity of use within that duration period, and (4) the total number of hours of respite that is used. It is not only plausible that families will vary in their patterns of use as conceptualized and measured in these different ways, but it is also likely that a different set of factors may account for the variation in the different measures of use. Therefore, to fully describe patterns of respite use and capture differences among families in their patterns of use, it is important to conceptualize and measure use in several different ways. The **intensity** of respite was defined as the number of hours used in each month. The **duration** of respite use was defined as the number of months between the client's first occasion of use and the last occasion of use. The **continuity** of respite use was measured as the ratio of number of months in which a family actually used the respite services relative to the number of months for which the family was eligible to use services. The **total hours** of respite used by a client is equal to the sum of all hours used over the eligibility period. (The **eligibility period** was defined as the period between enrollment in the demonstration project and departure from the project for any reason.)

Strategy for Data Analysis. Two sets of analyses were conducted to fully describe the patterns of respite use by clients. The first set of analyses focused on clients who used services for only a brief period. These analyses included all clients who limited their use of respite services to one or two months. Both descriptive statistics and logistic regression techniques were used to identify key characteristics of these brief users.

The second set of analyses focused on clients who used services for three or more months. Regression techniques and hierarchical linear modeling procedures were used to identify and describe their patterns of respite use.

Findings

Brief Users

Almost one third of the demonstration clients used respite services for only one or two months and the mean length of use was ten months. White clients were most likely to be brief users. Black/African-Americans were least likely to be brief term users of day care and Hispanic/Latino clients are least likely to be brief users of in-home. This pattern may reflect the success of the ADDGS demonstration with promoting programs that effectively serve traditionally under-served populations.

The decision by clients to continue or discontinue use of services is related to characteristics of the service providers. The positive relationship observed between brief user status and problem behaviors likely reflects the limited capacity of day care providers to care for persons with problem behaviors. As long as elders are able to function in a day care setting, they continue to use that service. When elder impairment becomes too high, families are likely to seek in-home services. Day care is most often used as a support system when caregivers must be away from home or when caregivers have other obligations that require their attention. When the impairment level of the elder increases to higher levels, adult children who cannot leave a parent home along are more likely to cease caregiving.

Brief users of in-home respite appear to constitute a sub-population of caregivers with unmet needs who have a greater need for professional health and household assistance. Consequently they tend to discontinue use of programs that are staffed by volunteers that do not provide health related services and that often do not have set fee structures

Extended Users

For extended users of respite, mean duration of service use is 16.2 months for day care clients and 14.9 months for in-home use. Day care clients use twice as many hours of service each month (50.3 versus 24.6) and almost three times (817 versus 283) as many hours of care over their full duration of service use.

Client characteristics are the primary predictors of the duration, continuity and intensity of service used. Persons with high levels of IADL impairment used day care services a shorter duration, but with greater intensity. Among users of in-home respite, higher levels of ADL impairment and problem behaviors were associated with more intense use of services. For users of both types of services, the number of hours of service used each month increased with duration.

Clients assisted by a spouse were more frequent users of in-home respite programs, but they used significantly fewer hours of respite each month than did their peers who were cared for by an adult child or other more distant relative. Elders with male caregivers used more respite services.

Different ethnic groups had distinct trajectories of day care use over time. Compared to Whites, Blacks/African-Americans used smaller quantities of service over a more extended period of time. Hispanic/Latino elders used high quantities of service for short periods. Notably, the two groups of minorities did not differ in the average total number of hours of day care used.

Middle-income elders were the highest users of in-home services. For this client group, in-home respite is probably the most economical solution for long term care because of limited discretionary money and ineligibility for Medicaid as a source of payment for nursing home care.

Two provider characteristics influence the intensity respite service use over time.

Families who sought respite from programs that offer health care services used services more intensely. This trend likely reflects higher levels of elder need. In general, clients used services more intensely when the maximum limit for services was higher, although they did not necessarily use more services over the duration of their use. This pattern suggests that arbitrary caps on services may impede effective distribution of resources among clients with different levels of need.

PRACTICE IMPLICATIONS

Accurate cost estimates for respite services cannot be made without clear knowledge of client variations in the duration, continuity, and intensity of respite use. When providers plan and budget for respite services, it is useful for them to consider the characteristics of their client population, which are directly linked to variations in patterns of use.

- It is important to offer multiple forms of respite to meet the needs of different segments of the client population and to provide ongoing support for families, as needs change over time.
- When designing respite services, attention should be given to both the level of care provided and the type of respite services offered.
- Limitations placed by providers on the number of hours of service available to clients are likely to create significant barriers to service use if they are not appropriately tailored to match client characteristics.

STUDY THREE: STAFF VIEWS ABOUT SUCCESSFUL STRATEGIES FOR ADDRESSING CULTURAL BARRIERS TO SERVICE

Purpose of Study Three

The purpose of study three was to provide a more detailed understanding of the issues confronting providers as they attempted to successfully develop and implement culturally appropriate support services for diverse populations. Qualitative methods were used to explore more fully the ethnic, geographic and familial contexts of service delivery from the perspective of service providers. Data were gathered through interviews with key service delivery staff who discussed successful strategies for addressing cultural and/or structural barriers to service use.

Methods

Sample. Fifty qualitative interviews were completed. Forty-two interviewees were frontline staff members and eight were administrators. Programs that targeted urban dwelling Hispanic/Latino families employed fifteen of the staff members and ten worked for programs that served urban Black/African-Americans. Of the twenty-five staff members employed by programs that served rural populations, eight provided respite to Black/African-American families while four served rural Hispanic/Latinos. The remaining thirteen staff members were employed in programs that served rural families of all ethnic groups.

Data Collection. Interviews were conducted by telephone and then tape recorded for later transcription. Questions followed an interview guide and proceeded in an open ended, in-depth format in accordance with standard qualitative methodology.

Findings

Staff members offered general and specific information about the qualities of the communities they served. The interviews revealed both unique beliefs and needs of the three target populations (rural, Black/African-Americans, Hispanic/Latinos) as well as needs that were shared by all three of the client groups. Staff members also described a range of strategies for successfully serving these client groups

Serving Rural Communities

Important Client Characteristics. Providers in rural communities stressed the importance of recognizing the unique culture of these areas. In general, rural individuals were relatively isolated and had fewer opportunities for education, medical care, and other services. There was a tendency to rely on oneself, one's family, and one's church, and a strong ideology of independence. The relationships to family and church were very strong and central within rural communities. Because of the small size of the communities, there was also an enhanced level of familiarity among residents. There was also a general distrust of outsiders, including service staff, service agencies, researchers, and government institutions.

A lack of general knowledge and understanding of Alzheimer's disease was pervasive. Most families were dependent upon their family doctors for dementia specifics. Unfortunately, rural physicians, especially those who have been practicing for a number of years, often had little training about Alzheimer's disease nor awareness of the possible treatments.

Barriers to Service Delivery. Providers reported that in the rural areas there was often a stigma attached to the use of support services because they were often viewed as welfare a public handout. This stigma created a serious barrier to service delivery, especially for less educated families. Additionally, rural clients preferred staff members of similar ethnicity, religion and gender to the elder. Providers also identified isolation of rural locations, shortage of trained

staff, limited resources, and transportation as barriers to delivering quality services in rural areas.

Serving Black/African-American Communities

Important Client Characteristics. Black/African-American communities were recognized for their strong sense of extended family and community ties. This client community had a greater prevalence of working caregivers, primary caregivers who were more distant relatives, and wider family involvement in caregiving. Providers observed that Black/African-Americans valued their ability to remain self-sufficient and “take care of their own”. They also shared a pervasive mistrust of government assistance as well as the medical system. Spirituality and organized religion had an important role, both to the Black/African-American community in general, and as a support structure for individual caregivers. The expression of respect among community members was also very important.

Barriers to Service Delivery. Two issues were identified by providers as particularly unique challenges for serving Black/African American communities. First, providers noted that families seemed to take the challenge of Alzheimer’s disease in stride and were realistic in dealing with the related care tasks. Consequently, they often did not seek or readily accept help. Younger caregivers, however, were more receptive to service use than older caregivers. Second, members of the Black/African-American community expressed feelings of initial reluctance to accept a White care provider. This reluctance appeared to be related to historical issues of mistrust and social mores between the groups. In addition to these unique challenges, staff members identified several structural barriers to providing services: scarce funding, distrust of government services, and suspicion of the medical research community.

Serving Hispanic/Latino Communities

Important Client Characteristics. Providers within the Hispanic/Latino communities stressed the wide diversity within this population which includes persons of many nationalities who vary greatly in culture, dialects, and etiquette. Many clients were monolingual Spanish-speakers with relatively low levels of literacy that resulted in isolation from mainstream services. These clients particularly valued one-on-one relationships with service providers. When using services, Hispanic/Latino families were most comfortable with bicultural staff members that were familiar with their community, their nationality, and spoke Spanish. Providers also reported that younger caregivers were more receptive to service use than older caregivers. Despite the diversity in cultural norms within the Hispanic/Latino community, providers noted a common expectation that the family unit should solve family problems and provide needed care. Additionally, gestures of respect were considered important, and differed by nationality.

Families in this community sometimes feared that Alzheimer’s disease was a form of insanity. Additionally, they believed that dementia symptoms were a “curse” or a punishment for previous “bad” behavior. Other common responses included religious explanation such as the caregivers’ cross to bear or the elder’s possession by evil spirits. These beliefs led families to seek non-medical cures. Many Hispanic/Latino families did not value Western medical treatments and if they did seek care from a physician, they were often not diagnosed appropriately.

Barriers to Service Delivery. The unique qualities of the Hispanic/Latino clients created several barriers to effective service provision. In every setting, language represented a significant barrier to service use for this group. Providers within the Hispanic/Latino populations also identified the strong cultural value of family caregiving, a pervasive mistrust of the government, a preference for folk or home remedies, and difficulties maneuvering through complex bureaucracies as barriers faced by these communities.

Common Barriers

Three themes were common among providers serving all three communities. Each group was described as having an ideology of self-sufficiency that emphasized reliance on family. Providers also perceived these client groups to have a general distrust of the government and of any services affiliated with it. Additionally each group was described as having a lack of knowledge about Alzheimer's disease.

Strategies for Overcoming Barriers.

Providers identified four general strategies that they used to address the barriers to service delivery in these communities. These strategies recognized the cultural beliefs of these underserved communities and can be characterized as both innovative and responsive to client needs.

First, when approaching clients in these underserved communities, providers described and emphasized their services, as programs that would complement and supplement, not replace family care. For example, within the Hispanic/Latino communities, providers were more successful in their outreach strategies when caregivers were assured that they were not alone in dealing with dementia, and that seeking assistance is not neglectful of familial duties. In rural areas, providers also attended to the concern of respite as a handout by charging a nominal fee for the services.

Second, to overcome resistance to formal support services, social aspects of care were emphasized and programs were designed to include activities that were familiar to the clients. For example, within the Hispanic/Latino communities, providers found it helpful to offer traditional food, and to celebrate national holidays of their clients' home countries. In general, successful programs strived to provide services in a friendly, home-like manner relying on familiar activities, often based in music or religion. Similarly, providers developed service activities around social themes in non-institutional settings, such as referring to support groups as "clubs" or "tea-time," which were more likely to be accepted by both Black/African-Americans and Hispanic/Latino clients. Support groups were also better attended when they were combined with a potluck dinner or luncheon.

Third, providers developed strategies to help families obtain better information about Alzheimer's disease and health care. Within the Hispanic/Latino communities, providers acknowledged folk beliefs as a place to begin in educating about dementia. Assistance with filling out forms and applications was also provided to help families negotiate health care systems and obtain benefits for which they were eligible. In rural communities, providers focused on empowering families in talking with their physicians to obtain a diagnosis or more medical information.

Finally, providers tailored and individualized services to better meet the unique needs and concerns of their client populations. For example, the prevalence of working caregivers in the Black/African-American community led some providers to conduct seminars within large workplaces, and to extend day care hours. Providers also noted the importance of instructing workers to address Black/African clients respectfully as Mister or Misses. To serve Hispanic/Latino clients, providers developed bilingual services and were successful at cultivating bicultural staff members. The small size of most rural agencies allowed providers to individualize care plans to match clients with familiar aides. Rural providers were also creative in devising solutions to the barriers bred by isolation. Examples included long-distance support groups and information newsletters, as well as more extensive transportation networks.

CONCLUSION

Major Themes

This set of related studies was undertaken with the knowledge that most service providers believe respite programs are both desired by, and useful for, families caring for persons afflicted with Alzheimer's disease. The focus of the research has been on the manner in which a diverse population of caregiving families used respite service, the beliefs of these families about caregiving and their preferences for services. The report includes a large number of findings regarding behaviors and preferences of family members who provide care for their relatives. These findings are summarized under four major themes.

1. There is great diversity among caregivers in the contexts within which they provide care and their beliefs about family and government obligations. These differences are primarily associated with ethnicity and the relationship of the caregiver to the care recipient.
2. Diversity among caregivers created a corresponding diversity in the types of services that caregivers seek and the manner in which they use respite services. Clear patterns were observed that indicate that caregivers seek and continue to use services that they perceive as useful to their caregiving context. Similarly, caregivers ceased using services that they perceived to be inappropriate or difficult to use. Indeed, almost one third of the clients included in this study were brief users who used services for less than two months.
3. Different types of respite services meet the needs of different service populations. The distinct differences in patterns of service use that were observed for different segments of the caregiving population underscore the importance for communities to offer a respite services in different formats. Optimally, a community would offer a continuum of services. Caregivers are active agents in choosing support services. The patterns of respite use observed in the longitudinal data suggest that the choices that caregivers make are influenced by both structural factors and by caregivers' perceptions of their own needs.
4. Provider characteristics influence the patterns of use or non-use of services as well as client satisfaction with services. When making decisions about service use, families judge the appropriateness of a service for their family context and the accessibility of the service. Three sets of provider characteristics were seen to influence clients' service use: *the amount and level of service, quality of staff, and effective communication with family members.*

Practice and Policy Implications

When the broad array of findings is considered together several general implications for program design and service delivery can be delineated.

1. The efficient and effective use of program resources dictates careful consideration of patterns of service use for different segments of the target population. These studies identified a range of different long term patterns of service use that are associated with the relationship of the caregiver to the elder and with ethnicity. To plan for future service needs, it is important to consider these trajectories in conjunction with the prevalence of the different segments of the population in the programs' catchment area.
2. When developing a new respite program, it is important to create a service that complements other services available in the community in an effort to make a full continuum available. Not all programs are appropriate for all caregivers. If a community can offer only one form of respite, it is important to learn as much as possible about the prevalence of

different types of caregiving contexts in the community in order to best meet the community's needs.

3. Existing programs may want to carefully consider the characteristics of the clients they are currently serving and note the characteristics of those who are going unserved. All policy decisions regarding availability of services reflect values about who should be served and at what cost. It is not always possible for programs to serve all segments of the caregiving population. However, it is important for policy makers to consciously consider which groups of persons they choose to serve. For example, day care programs that are not offered daily or throughout the normal workday clearly will not serve the majority of employed caregivers. A well-planned program will consider such issues carefully.
4. Once a respite program has been developed, it is important to target the services to the appropriate segments of the caregiving population. Programs that carefully target services and/or alter eligibility rules or the number of hours of service available will be able to reduce the number of families that enroll in services for only brief periods. These families can be costly to programs due to the high costs associated with the initial enrollment of clients.
5. The hiring and training of competent, caring workers is a key element in creating a successful respite program. All staff members should be trained to be sensitive to the diversity of caregiving situations and to communicate with families in an open, effective, and clear manner. Existing programs might want to assess the communication skills of their staff members and/or modify the ways in which they communicate information about the services to families. Attention needs to be given to both the content of communications and the way in which information is delivered. Clarity is essential.
6. Careful consideration should be given to policy decisions that place limits on access to respite services. For example, the level at which services are capitated clearly influences service use. Not all families benefit from the same dosage or amount of respite and it is possible for programs to be ineffective because the amount of service offered is insufficient.